



Determinants of young Adult Social well-being and Health
A survey of young people from different ethnic groups in London



Participant Information Sheet I

DASH Pilot Study 2011-2012

- **What's DASH all about?**

You are being invited to take part in the DASH (Determinants of young Adult Social well-being and Health) pilot study, a follow-up research study involving around 300 young people. You have previously taken part in other DASH surveys - in 2003/2004, you took part in the DASH Study about the lives and health of young people in secondary school and a follow-up school survey in 2005/6. In 2010, you took part in the DASH postal survey and we are now planning to pilot a comprehensive follow-up survey among DASH participants. We want to find out about any changes in your health and about changes in the things you think influence it. The following information sheet outlines the details of the study and what participation will involve. Please take the time to read the information carefully and discuss it with others if you wish.

- **Why me?**

We want to get as broad a view as possible about what affects the health of young people in London. You were originally chosen to participate in this study as we wanted to collect information from a wide range of young people from different communities. We plan to monitor the health of the DASH participants throughout their lives. The information we collect will enable us to examine if and how health changes from childhood to adulthood and what promotes good health for everyone in the long-term. It is, therefore, really important that we collect information from the same young people again.

- **What do I have to do?**

You do not have to take part in the study, but if you do it will be of great help to us. We would like you to fill out a questionnaire we will send you which includes questions about your home and family life, your health and lifestyle, and how you feel about different aspects of your life (which should take 30-40 minutes to complete) and a questionnaire in which to recall your previous day's dietary intake (30-60mins). You do not have to answer all the questions if you don't want to. If, for any reason, you are unable to complete the questionnaires in advance, we can assist you when you meet with one of our study nurses.

We would like you to meet with one of our study nurses or researchers to complete some physical measures. You can choose to be seen in a place that is most convenient for you. For example, you can be seen at home, in a local GP surgery, at a University (e.g. Kings College London where the study office is located or your own university if you are attending university/college), at an NHS Clinical Research Facility, a Clinical Research Centre, at your local community pharmacy or at your workplace. The physical measures we would like to take will be your pulse, blood pressure and artery flexibility (this involves wearing a blood pressure cuff for most of the visit, which will only inflate at certain points throughout the interview, and will not adversely affect your circulation. We will also measure the length of your trunk to estimate the time the pulse takes to travel between two sites in the body), height, weight, and waist circumference, lung function and internal body fat (measured by directing a very mild electric impulse through electrodes attached to your hand and foot, which is entirely safe and will not hurt at all (it is called bioimpedance)). We expect the physical measures to take 20 – 25 minutes to complete. We will ask all female participants if they are pregnant, or likely to be pregnant, as pregnant women should not participate in bioimpedance measures.

If you agree, we would also like to take a blood sample which will give us biological markers of your health. We would like to take approximately 25ml of your blood, which is about 5.5 teaspoons. Collecting the



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<http://dash.sphsu.mrc.ac.uk/>

blood will take about 15 minutes. We will tell you a little more about the purpose of the blood sample below. You can take part in the study without giving a blood sample if you wish.

Finally before you leave the nurse will ask if you would mind wearing a little monitor (called an ActivPal) on your leg for five days to measure your usual physical activity. The ActivPal monitor is very small, around the size of a phone battery. We will arrange collection of the monitor at your convenience.

Before the nurse collects any information from you, s/he will ask you to sign a consent form agreeing to take part in the study. During the session, you can choose not to answer any questions, refuse any physical measures or bloods you do not want taken or stop the study at any time. We will also ask you to sign a consent form before we take the blood samples and again, you can refuse any sample at any time. If you choose to do the physical measures and/or give a blood sample, after we have analysed your data, we will send some of your results back to you, and to your GP if you wish.

- **Why are we asking for a blood sample and what will happen to it?**

The blood sample is required to give us more detailed information about the general health of the people taking part in the DASH study. However, before you agree to donate a blood sample, it is important that you understand what will happen to it now and how it may be used in research in future.

- First, a sample will be used right away for general health screening. This will involve testing the sample for levels of lipids or fats (e.g. cholesterol) in the blood and other common markers of health (e.g. blood cell count, liver and kidney function, markers for future heart problems and diabetes). It will not involve testing for blood borne viruses, HIV or Hepatitis B or C. We realise that the results of the health screening may be of importance to you. At your request, we will send you a copy of selected results and, with your permission, a copy to your GP together with the results of some of the physical tests. This is covered specifically in the consent form that you will be asked to sign.

Secondly, we wish to store a sample of your blood for future tests for any further markers of health in blood cells that are discovered. We would also like to store a sample of your DNA (the substance that makes up your genes) because research has shown that genetic make up may influence the risk of developing certain illnesses in different groups in the population. To do this we will extract some DNA from a portion of your blood sample. The Blood/ DNA sample will be assigned a unique code so that your identity will be protected at all times then stored by the MRC for use in future research into the genetic basis for disease and the response to treatment. We will not give you individual genetic information now or in the future because we cannot say what bearing it might have on your individual health.

- **Your rights concerning the stored Blood/ DNA sample**

You should note that the MRC *would not* own your sample but would act as custodian and as such be responsible for its secure storage and for appropriate use in future research and development.

Note also that you could withdraw your Blood/ DNA sample at any time in the future. The MRC research team would undertake to arrange for the sample to be de-coded, identified and destroyed if you requested this by writing to:

Mrs Catherine Ferrell
Survey Manager
MRC Social and Public Health Sciences Unit
4 Lilybank Gardens
Glasgow
G12 8RZ



- **Will my information be confidential?**

All information given to us will be strictly confidential. Your questionnaires have been given a unique number and we will detach the page in the main questionnaire with information which could identify you. This means that you cannot be recognised from the data you provide in the rest of the questionnaire. The questionnaire, physical measures and blood sample data, and any identifiable information, will be kept securely and separately by the researchers.

- **What happens after the interview?**

During the interview we will ask you if we can continue to follow up on your health by accessing information held by the NHS Information Centre (<http://www.ic.nhs.uk/>) and records maintained by the General Register Office (<http://www.gro.gov.uk>). By linking this information with the interview data, we can look at how people's lifestyles and circumstances can have an impact on their future health. This information is confidential and will be used for research only.

At the end of the nurse interview, you will be asked if you would like to wear a little monitor for five days so we can measure how much physical activity you did as your regular routine. If you agree, he/she will show you how to attach it and a member of the DASH team will contact you regarding collection of the monitor. Within 3 weeks of the interview, a researcher will contact you to repeat the dietary assessment over the phone so that we can have a complete picture of your diet. We will also ask you about your general experience of the study to help us evaluate what was done well and/or how the study can be improved. We will also ask your permission to contact you again in the future to send you information about the findings of the study as they become available, and perhaps to ask you to take part in more detailed studies to follow up on findings from this interview. We are not asking you to take part in a future study now but, with your permission, we may want to contact you about one in the future.

- **Is there any cost to me in taking part?**

The main cost to you is your time as it will take around two hours 30 minutes to complete all parts of the study. If you travel to a GP surgery and incur any travel costs, these will be reimbursed to you. And, to thank you for taking part, we will send you a £25 'Love to Shop' voucher. This can be spent in hundreds of high street stores. More details can be found at <http://www.highstreetvouchers.com/gift-vouchers/> We will also enter all those who take part in the feasibility study into a prize draw to win an iPad.

- **What will you do with the results of the study?**

The results will be published in research journals and in reports for people working with different communities. They will also be presented at meetings with a wide range of audiences, including researchers and policymakers, to promote practices that could benefit health for everyone. We will also feedback to anyone who takes part using newsletters and the DASH study website. You will not be identifiable from any report or publication.

More generally, the data we gather from you and other study participants are very important and would be very useful to other researchers. We will therefore ask you during the interview, if you are happy for us to give other trusted researchers access to your anonymised data. This will increase the understanding of health that can be gained from the data you have provided. We will only share your anonymised data with other trusted researchers if you agree, and will not otherwise share your data with any third party.

- **What are the possible disadvantages and risk of taking part?**

Apart from the time required to complete the survey, no known disadvantages or risk are associated with taking part.

- **Who can tell me more about it?**

If you have any questions or queries about taking part you can contact us on FREEPHONE 0800 298 0024, at our study office on 0207 848 4505 or by email: dash@sphsu.mrc.ac.uk and we will ensure that a researcher gets back to you as soon as possible. You can also find further information about the DASH study and previous publications on our website: www.sphsu.mrc.ac.uk/study-sites/dash

- **Who can I speak to if I have any concerns?**

If you would like to speak to someone who is aware of the study but who is not directly involved in the research team, or if you have a concern or complaint, you can contact the survey manager, Catherine Ferrell, at the address and phone number below or by email at c.ferrell@sphsu.mrc.ac.uk

- **Who is organising and funding the research?**

The DASH study is funded by the Medical Research Council, a government funded but independent body. The study is being carried out by scientists from the Medical Research Council/Chief Scientist's Office Social and Public Health Sciences Unit, Glasgow, who specialise in studies of social conditions and their links to health.

- **Who has reviewed the study?**

The study has been reviewed and approved by a Research Ethics Committee (for further information, please see website <http://www.nres.npsa.nhs.uk/>) within the NHS.

**THANK YOU FOR TAKING THE TIME TO
READ THIS INFORMATION SHEET.**

By taking part in this study you are contributing to research that aims to find out how best to promote good health for everyone throughout their lives, regardless of their background.